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The Lived Experience of Parents Caring for a Child With Type 1 Diabetes

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ABSTRACT

Type 1 diabetes is the most common chronic metabolic condition seen in children and adolescents. Parents of children with Type 1 diabetes are responsible for carrying out a demanding treatment regimen on a daily basis, to prevent short- and long-term complications related to blood-sugar control. Parents can experience significant stress related to this role, but there is limited in-depth qualitative research on the parental experiences of caring for a child with Type 1 diabetes. Understanding the experiences of parents can contribute to better parental and child adjustment to the illness. The present study explored parental experiences by using Interpretative Phenomenological Analysis (IPA) of in-depth semi-structured interviews with 17 parents of children with Type 1 diabetes.

In this study, parents experienced a profound biographical disruption from the moment their child was diagnosed, which undermined their confidence in the ability to care for their child. Parents likened this to the experience of having a new baby. They used repair structures to reconstruct parental identity based on the idea of normality. These involved normality through typical childhood experiences, embracing a new normality, and preserving family normality. Looking after a child with diabetes was also dominated by the 'constant-ness' of the disease, driven by a need for constant vigilance and better management in the context of an unpredictable body. Parents responded to some of the embodied experiences of the child through their own embodied acts of caregiving. They also made comparisons between diabetes and other conditions as a way of coping with the embodied unpredictability of childhood diabetes. Parents' accounts of resilience in the context of Type 1 diabetes reflected a mainstream understanding of resilience as an individual attribute or capability.

However, from their talk of navigating through daily challenges, an alternative conceptualisation of resilience for these parents is presented as 'doing' resilience. 'Doing' resilience also involved a separation of actions and emotions of the parents, which supported the daily 'doing' of diabetes. These findings highlight the psychosocial implications of parenting a child with Type 1 diabetes. They indicate a need to acknowledge the profound impact on the parents' lives and the ways that they attempt to cope with the demanding caregiving responsibilities. Understanding these lived experiences can enable health professionals to provide better support in making sense of and coping with the changes in parents' lives.

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DEDICATION

To Mahin and Myran

Always keep your dreams alive. I know you can make them happen.

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PREFACE

The thesis is in the form of a thesis with publication. The first chapter presents an introduction to the present research by providing relevant background literature. Chapter 2 provides a detailed account of the methodology undertaken. Chapters 3, 4, and 5 present the findings of the analysis written up as individual manuscripts. Chapter 6 discusses the main findings and implications arising from the research, reflexivity, methodological considerations, and suggestions for future research. For readability, references have been provided at the end of each chapter.

The first manuscript has been published online in the *Journal of Child and Family Studies* (2017). The second and third manuscripts will be submitted for publication. As the three publications are based on the findings from one single study, some repetition in each of the manuscripts was anticipated, especially in the introduction and methodology sections.

My supervisors Dr. Mary Breheny, Dr. Kirsty Ross and Dr. Joanne Taylor provided guidance and feedback on the manuscripts, similar to their assistance with the other chapters of this thesis. Hence, they are included as co-authors for the publications included in this thesis.

